

ASPECT Program

(Advocacy, Support, Perspective,
Education, Communication & Training)

Why is the ASPECT Program needed?

The patient has been described as the ‘greatest untapped resource in healthcare,’ and patient engagement termed ‘the blockbuster drug of the century.’

Health-focused efforts must incorporate factors identified by the patients and allies themselves, and the only way to achieve this is by having robust programs in place to incorporate their voices. To date, no such program exists to support the patient’s role as a leader in vision and eye health in the U.S.

What is the ASPECT Program?

To address the lack of a program supporting patients in vision health, Prevent Blindness developed the ASPECT Program– Advocacy, Support, Perspective, Education, Communication, and Training– which aims to strengthen our patient empowerment efforts for vision into a coordinated program that engages the individual in a more comprehensive manner. The goal of the ASPECT Program is to empower individuals to be engaged in their eye health from every direction and in every way.

The Prevent Blindness ASPECT Program is recruiting both allies–

individuals who are at risk of or care for someone with vision loss– as well as patients who have experienced vision loss due to an eye disease or injury.

Who Participates in the ASPECT Program?

Patients/allies who are engaged in all aspects of their health not only experience better outcomes, but are able to contribute to advancements in the healthcare of their communities. ASPECT will create a resource of patients and allies, acting in leadership roles to make a difference specifically in improving the experience of care and promoting a strong quality of life.

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The consequences of patients not engaging are borne most heavily by the patients themselves and their families, in the form of emotional, physical, social, and financial costs; but it also has a significant impact on social and healthcare systems with respect to duplication of efforts, decreased capacity, wasted resources, suboptimal outcomes and increases in health inequities.

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A – advocacy: Provide opportunities to shape policy and practices that promote healthy vision, access to care, and reduction in vision impairment

S – support: Provide resources, peers, and professionals that will help individuals understand their conditions, the disease process, and work toward an improved vision-related quality of life

P – perspective: Promote inclusion of patient perspectives at the local, state, and national levels leading to effective and sustainable systems, processes, and outcomes

E – empowerment: Establish a pathway for participants from self-discovery, to peer-support, to community engagement as it relates to their vision and eye health

C – communication: Create a communication system that provides evidence-based education, peer-to-peer support, and consistent information from a trusted source

T – training: Build skills in patients and individuals that foster fully inclusive, confident, and collaborative work with professionals, clinicians, and policy-makers

How will the ASPECT Program be implemented?

From the start, the ASPECT Program has been intentionally carried on a collaborative basis; meaning together with participants, we co-produce the learning experiences from meetings and workshops, communication approaches, and establishing a Patient/Ally Leaders Expert Advisory Group for the life of the program. Through this new approach all aspects of needs and opportunity for growth will be addressed. [See sidebar]

What will the ASPECT Program accomplish?

Through their participation in the ASPECT Program, patients and allies will:

- *Become versed and involved in the vision condition that impacts their life and understand the disease process*
- *Receive our V2 (Voice for Vision) advocacy training which creates powerful voices addressing vision conditions in local, state, and national settings*
- *Gain access to diverse platforms in which they can lead the change in policies resulting in an improved quality of life for those at risk of or experiencing vision loss*

We recognize that the individuals impacted by vision loss have the most powerful voice when it comes to making the case for

improving practices and policies related to eye health– but they might not have the skill sets or opportunities to raise their voices. The ASPECT Program will change all of that.

What are the long-term outcomes of the ASPECT Program?

- *A patient-driven curricula promoting engagement in eye disease and eye health preservation is implemented*
- *Diverse eye health organizations have an opportunity to collaborate in a program that will result in passionate and engaged advocates that will further drive each of their missions*
- *Each cohort of patient graduates from the ASPECT Program will serve as an ongoing resource for individual or peer-to-peer education, support groups, eye disease campaigns, educational resource material development, provide committee membership or leadership on behalf of eye health, or advocate at all levels for improved access to eye care and treatment*
- *Individuals are provided with tools and education that gives them control of their eye disease in a new way, allows the participants to be a leader for eye health, and to have their story and experience recognized for its importance*

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- *Best practices in patient engagement will be developed and shared via diverse communication channels*

How can I engage with ASPECT?

Individuals/groups interested in engaging with ASPECT should contact Julie Grutzmacher, Director of Patient Advocacy and Population Health Initiatives (jgrutzmacher@preventblindness.org) to determine opportunities for direct collaboration or support.

Who supports the ASPECT Program?

The ASPECT Program is generously supported by Novartis, Amgen, Genentech, Apellis, Astellas, Johnson & Johnson, Kyowa Kirin, Mallinckrodt Pharmaceuticals, Regeneron, Spark Therapeutics, Biotechnology Innovation Organization, The AR and JR Peacock Trusts, Alexion, Viridian, and Alkeus.

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